



# Missouri First Steps

Working together with Missouri families  
to make a difference.

## Fiscal Year 2006



Missouri Department of Elementary and Secondary Education  
First Steps Toll-Free Number: 1-866-583-2392

# EXECUTIVE SUMMARY



First Steps is Missouri's early intervention program for young children (birth to age 3) who have physical or mental disabilities or serious developmental delays. Established in 1994, the program is authorized under the federal Individuals with Disabilities Education Act (IDEA). Working through a network of regional offices and hundreds of independent therapists and service providers, First Steps helps parents help their children as they confront the daunting challenges of raising an infant with a major disability or developmental delay.

This report offers a detailed review of the operations of Missouri's First Steps program during 2005-06. It presents, for the first time, a county-by-county breakdown of participation in First Steps. Highlights of this report include:

- 7,646 children were involved in First Steps in some capacity during the year.
- First Steps is supported primarily by state and federal funds. The total appropriation for First Steps services during 2005-06 was \$26.6 million, or about \$250,000 less than the previous year. The total First Steps budget consisted of about \$13.2 million in state funds and about \$12.5 million in federal funds, including Medicaid.
- Senate Bill 500, enacted in 2005, required families (based on their ability to pay) to begin contributing to the costs of First Steps. This law also required private insurance, if available, to begin covering some First Steps services. These provisions were implemented late in 2005-06 and had little financial impact during the year.
- Families continue to give First Steps high marks, indicating that the program provides valuable support and assistance to families and children. In a recent survey, for example, 98% of participating families said that early intervention services helped them enhance their child's development.

We hope this report gives you a better understanding of the First Steps program and the positive impact it has on Missouri children and families.



# Working Together to Make a Difference



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# ***Introduction***

First Steps is Missouri's early intervention system established under the requirements of Part C of the Individuals with Disabilities Education Act (IDEA) serving infants and toddlers (birth to 3) who meet state eligibility criteria. The Missouri Department of Elementary and Secondary Education (DESE) serves as the lead agency for the program. This report attempts to provide system performance information in order that the reader may have a better understanding of the scope, accomplishments and costs of the Missouri First Steps system. Yearly comparative data will help in the analysis of the program across multiple years.

The Missouri First Steps system includes the following components:

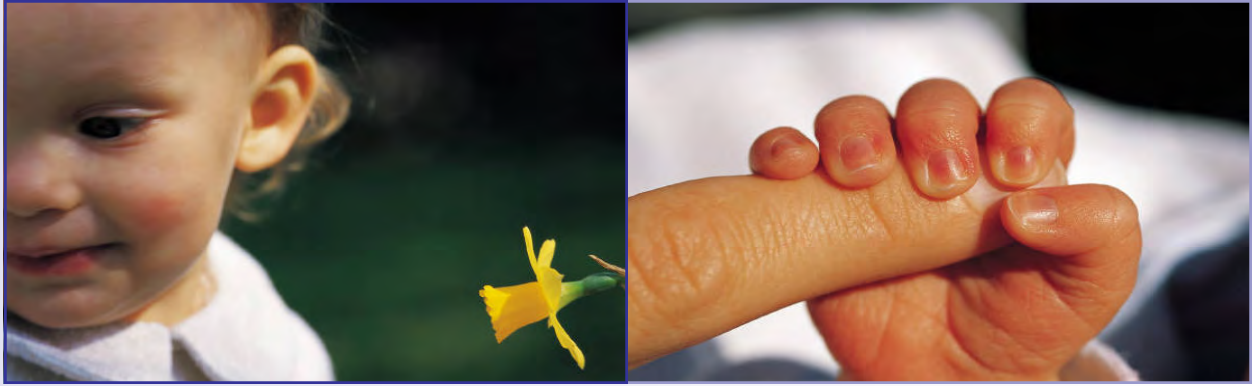
- Ten (10) System Point of Entry (SPOE) regional offices which handle referrals and eligibility determinations for the program. Sixty percent (60%) of all on-going service coordination is also handled by the SPOE office.
- Interagency collaboration with The Department of Mental Health Regional Centers to provide forty percent (40%) of on-going service coordination.
- A network of approximately 3,000 independent service providers.
- A Central Finance Office (CFO) responsible for provider enrollment, claims processing, including family cost participation and insurance processing, and data collection.
- Four (4) contracted regional consultants whose responsibilities include regional training for all First Steps providers and offices, support for local child find and public relations activities and general coordination between the lead agency and the regional SPOE/DMH offices.

The First Steps system in Missouri is made up of dedicated professional individuals, agencies, contractors and lead agency staff who provide outstanding services and supports to eligible children and their families. First Steps is a program that state and local officials, tax payers, enrolled families, and stakeholders can be proud of.





# ***First Steps Belief Statements***



*The mission of the Missouri First Steps Program is to provide a support and service system designed to improve the family's capacity to enhance their child's development and learning and to increase their child's participation in family and community life.*

*First Steps believes that:*

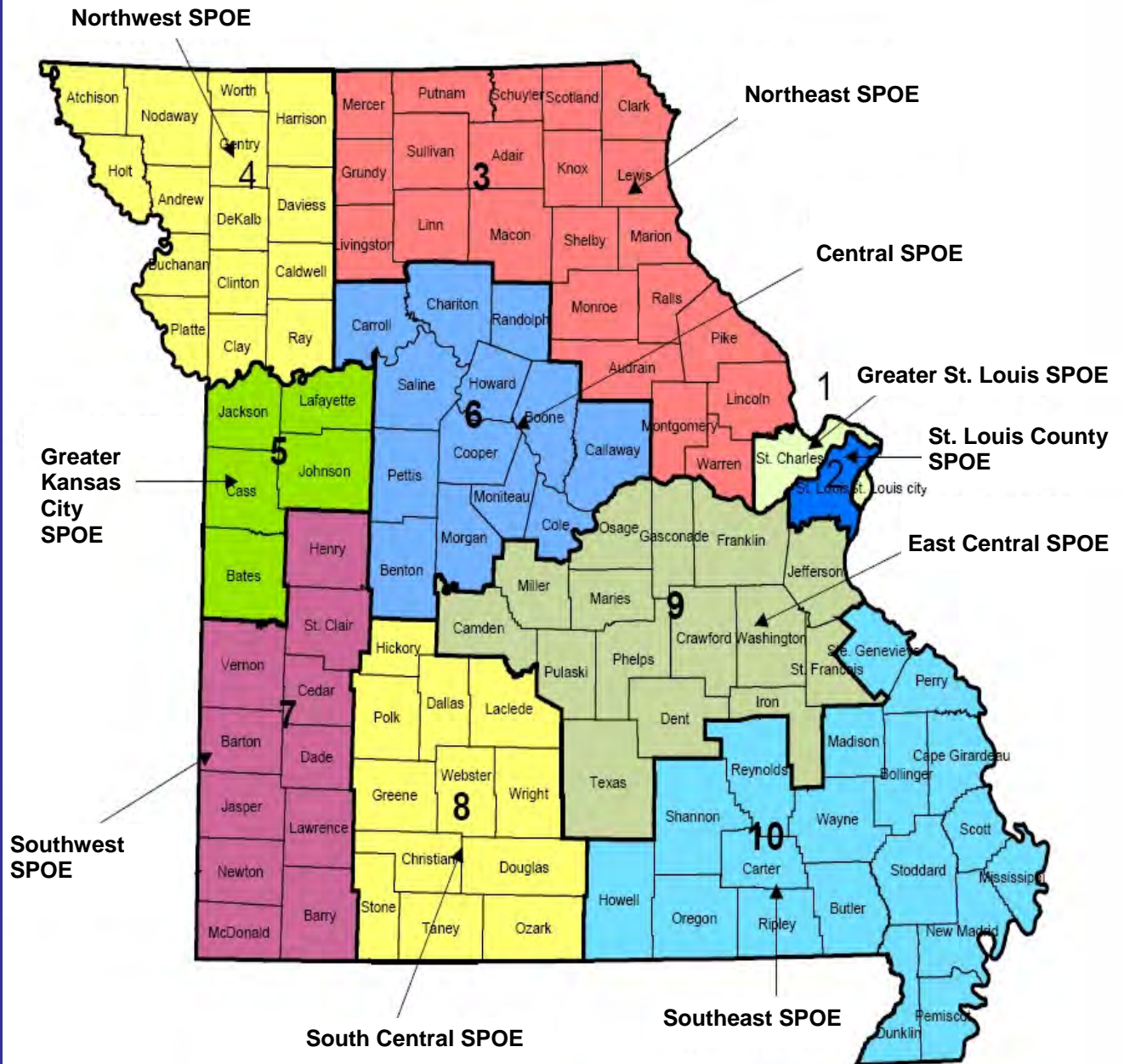
- *Families are decision makers and the child's first teacher.*
- *Effective services are designed around and promote family strengths.*
- *Effective services are culturally competent.*
- *Effective services are provided in the context of the child's and family's natural routines.*
- *Effective services are provided in natural environments.*
- *Services and supports are individualized.*
- *Competent providers focus on family competence.*
- *Early identification and family engagement are critical to early intervention.*

***Effective early intervention requires an active partnership that includes involvement by the family and caregiver in every early intervention service.***



# Missouri First Steps

## System Point of Entry (SPOE) Regions



To make a referral to First Steps, call **1-866-583-2392** (toll-free).



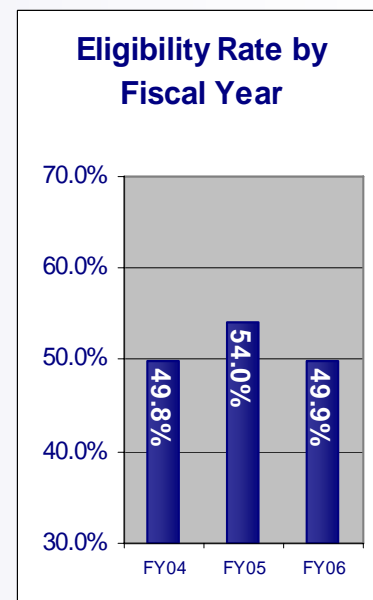
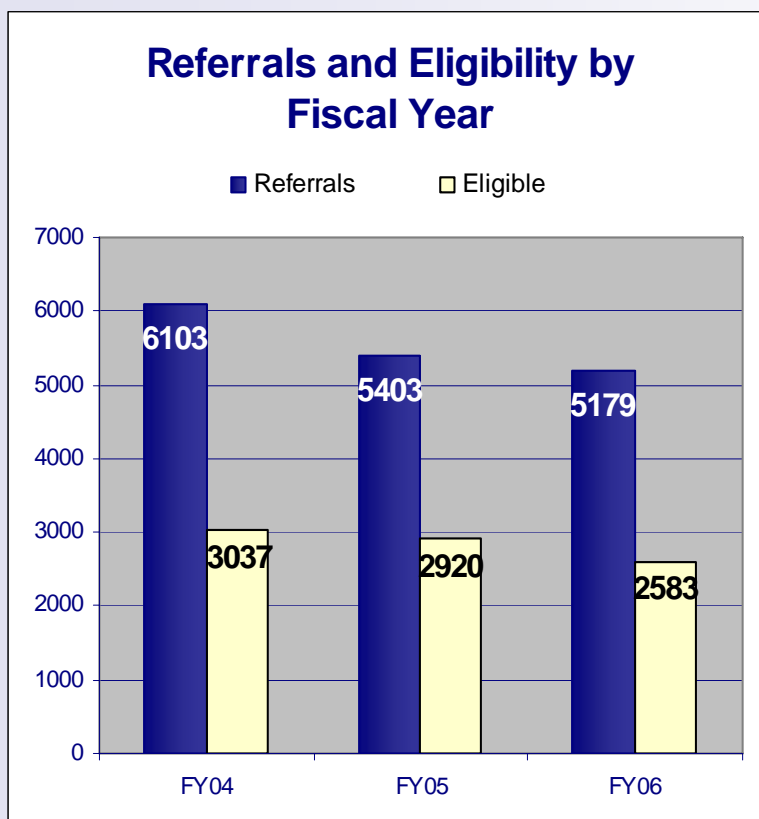
# Referrals

*The Referral is actually the first "service" that a child and his/her family receive from the First Steps system.*

The SPOE system ensures that all Missouri children and their families have equal access to early intervention services *regardless of their location within the state*. Building a strong network between the SPOE and primary referral sources in a community assists in the early identification and referral of potentially eligible children.



***How many children are referred each year, and how many are found eligible?***



# Referrals

## Who is referred to First Steps?

<b>Referrals by Age at Referral, FY06</b>	<b>Referrals</b>	<b>Eligible Children*</b>	<b>Eligibility %</b>
<1 year old	1,850	1,018	55.0%
1-2 years old	1,506	756	50.2%
2-3 years old	1,818	809	44.5%
3+ years old	5	0	0.0%
<b>TOTAL</b>	<b>5,179</b>	<b>2,583</b>	<b>49.9%</b>

## Who refers children to First Steps?

<b>Referral Sources and Eligibility, FY06</b>	<b>Referrals</b>	<b>Eligible Children*</b>	<b>Eligibility %</b>
Parent	2,446	1,265	51.7%
Parents As Teachers	637	253	39.7%
Neonatal Intensive Care Unit (NICU)	532	373	70.1%
Hospital (other than NICU)	511	279	54.6%
Physician (including Psychologists)	347	155	44.7%
Social Service Agency (includes DFS)	209	39	18.7%
Other health care provider	110	58	52.7%
Child Care Program/Provider	102	52	51.0%
Public Health facilities/providers	88	42	47.7%
Head Start/Early Head Start	61	18	29.5%
Child Abuse Prevention and Treatment Act	61	6	9.8%
Other LEA program	35	22	62.9%
Dept. of Mental Health (DMH)	33	16	48.5%
Dept. of Health & Senior Services (DHSS)	7	5	71.4%
<b>TOTAL</b>	<b>5,179</b>	<b>2,583</b>	<b>49.9%</b>

\* "Eligible Children" refers to those children who were found eligible for First Steps and received IFSPs.

**NOTE:** For specific referral and IFSP information by county see page 14.



# Eligibility

**Children between the ages of birth and 36 months who have been determined to have one of the following conditions are deemed eligible for First Steps services:**



**A. A diagnosed physical or mental condition associated with developmental disabilities or has a high probability of resulting in a developmental delay or disability.**

The state of Missouri has adopted the following conditions to meet the definition of "diagnosed physical or mental condition that has a high probability of resulting in a developmental delay".

1. Conditions diagnosed at birth or within 30 days post birth (newborn conditions)
  - a. Very Low Birth Weight (VLBW; less than 1500 grams) with one or more of the following conditions:
    - Apgar of 6 or less at 5 minutes
    - Intracranial bleeds (Grade II, III, or IV)
    - Ventilator dependent for 72 hours or more
    - Asphyxiation
2. Conditions diagnosed (Neonatal/Infant/Toddler Conditions)
  - a. Genetic Conditions known to be associated with mental retardation or developmental disabilities including but not limited to:
    - Down Syndrome
    - Cri-du-Chat Syndrome
    - Klinefelter's Syndrome
    - Trisomy 18 (Edward's Syndrome)
    - Trisomy 13 (Patau's Syndrome)
    - Turner's Syndrome
    - Triple-X Syndrome
    - Fragile X Syndrome
    - Prader-Willi Syndrome
    - Pierre Robin
  - b. Additional conditions known to be associated with mental retardation or developmental disabilities including but not limited to:
    - Hypoxic-Ischemic Encephalopathy (HIE) and at term (36 weeks gestation or more)
    - Cranio-facial anomalies (i.e., cleft palate, etc.)
    - Epilepsy/Seizure Disorder
    - Spina Bifida
    - Blindness, including visual impairments
    - Macro/Microcephalus, including Hydrocephalus
    - Deafness, including hearing impairments
    - Fetal Alcohol Syndrome
    - Cyanotic Congenital Heart Disease
    - PKU (phenylketonuria)
    - Cerebral Palsy
    - Viruses/bacteria (Herpes, syphilis, cytomegalovirus, toxoplasmosis, and rubella)
    - Acquired Immune Deficiency Syndrome (AIDS)
    - Autism Spectrum Disorders



# Eligibility

Other conditions known to be associated with mental retardation or developmental disabilities to be considered for eligibility must be based upon informed clinical opinion by Board-certified neonatologists, pediatricians, geneticists, and/or pediatric neurologists. These physicians may refer a child by indicating the specific condition and documenting the potential impact of the condition in any of the five developmental areas.

**B. A developmental delay, as measured by appropriate diagnostic measures and procedures emphasizing the use of informed clinical opinion, is defined as a child who is functioning at half the developmental level that would be expected for a child developing within normal limits and of equal age.**

In the case of infants born prematurely, the adjusted chronological age (which is calculated by deducting one-half of the prematurity from the child's chronological age) should be assigned for a period of up to 12 months or longer if recommended by the child's physician. The delay must be identified in one or more of the following areas:

1. cognitive development
2. communication development
3. adaptive development
4. physical development, including vision and hearing
5. social or emotional development

<b><i>Eligibility Reasons for Children with Active IFSPs (12/1/2005)</i></b>	<b>Children</b>	<b>% of Eligible Children</b>
<b>Confirmation of Developmental Delay</b>	1,415	41.5%
<b>Medical Condition Associated with Mental Retardation/Developmental Delay Exists - OR- Physician Confirmation of Other Condition Associated with Mental Retardation/Developmental Delay</b>	1,343	39.4%
<b>Very Low Birth Weight</b>	648	19.0%
<b>TOTAL</b>	3,406	100.0%

## **C. Services to Children considered to be "At Risk" –**

It is the policy of the State of Missouri to not include children considered to be "at risk" of having substantial developmental delays for eligibility in the Part C system under this application. The phrase "at risk" includes infants and toddlers who are not otherwise covered by the definitions described previously.



***The Individualized Family Service Plan (IFSP) is a document that reflects a family's concerns, priorities and resources with regard to the development of their infant or toddler.***

Families participate as full partners in the planning, development, implementation and review of their IFSP. The IFSP represents a commitment to eligible children and families that:

- Their unique, individual needs are considered and addressed.
- An individualized plan of action is developed to meet these needs.
- They participate as equal team members in the initial development and subsequent reviews of the IFSP.
- Appropriate levels of early intervention services are provided.
- They have choices about who provides these services.
- Services are provided in natural environments and are family-centered. They will focus on enhancing the family's capacity to respond to their child's developmental needs emphasizing their everyday routines and activities.
- Their procedural safeguard rights are protected.



<b>Active IFSPs by SPOE Region (based on 12/1/2005 child count) *</b>	<b>Active IFSPs</b>
Region 1 (Greater St. Louis)	468
Region 2 (St. Louis County)	629
Region 3 (Northeast)	140
Region 4 (Northwest)	280
Region 5 (Greater Kansas City)	588
Region 6 (Central)	257
Region 7 (Southwest)	149
Region 8 (South Central)	339
Region 9 (East Central)	379
Region 10 (Southeast)	177
<b>TOTAL</b>	<b>3,406</b>

<b>Active IFSPs by Race/Ethnicity (based on 12/1/2005 child count)</b>	<b>Active IFSPs</b>
American Indian/Alaska Native	6
Asian/Pacific Islander	58
Black/African American (Not Hispanic)	507
Hispanic/Latino	117
White (Not Hispanic)	2,718

<b>Active IFSPs by Gender (based on 12/1/2005 child count)</b>	<b>Active IFSPs</b>
Male	2,133
Female	1,268
Unknown	5

\* The SPOE regions represent the reconfiguration that occurred February 1, 2006. Prior to February 1, 2006, there were 24 SPOE regions in the State of Missouri.

# Services

## Who coordinates services for enrolled children and their families?

% of Children with IFSPs as of 12/1/2005 by Service Coordinator	
SPOE-employed Service Coordinators	69%
DMH-employed Service Coordinators	31%

As established by interagency agreement, DESE through the SPOE contractors is responsible for 60% of the on-going service coordination. The Department of Mental Health (DMH) is responsible for the remaining 40% of on-going service coordination.

## What services are being delivered?

First Steps Services for Children with IFSPs as of 12/1/2005 *						
Service Type	Delivery Type					
	Direct Child Service	Consultation/Facilitation with Others	Evaluation/Assessment	Family Education/Training/Support	Other	TOTAL
Speech Language Pathology	2,797	490	300	81	42	3,710
Occupational Therapy	2,286	488	201	43	21	3,039
Physical Therapy	2,168	470	120	34	17	2,809
Special Instruction	1,763	427	184	83	131	2,588
Nutrition Services	301	107	33	43	0	484
Assistive Technology	0	0	0	0	467	467
Special Instruction-ABA	174	49	8	15	2	248
Audiology	65	7	17	24	31	144
Nursing Services	71	35	16	16	1	139
Bilingual Interpretation	101	0	12	0	6	119
Social Work	35	12	24	36	0	107
Transportation & Related Cost	0	0	0	0	92	92
Medical Services	0	3	11	0	0	14
Sign Interpretation	7	0	0	0	0	7
Vision Services	2	0	0	0	0	2
<b>TOTAL</b>	<b>9,770</b>	<b>2,088</b>	<b>926</b>	<b>375</b>	<b>810</b>	<b>13,969</b>

\* This represents all active authorizations for all active children with IFSPs. It is a duplicated count, meaning if a child has three separate active authorizations for one service on the list, all three are included in the total.





# Leaving First Steps

Most families continue with First Steps until their children turn three years old or no longer need services and supports. Families are connected with new community resources as the transition process unfolds, the most common being Early Childhood Special Education (ECSE) through the local school district. **Children exited the program between July 1, 2005, and June 30, 2006, because of the following reasons:**



Exit Reasons for Children with IFSPs (FY06)		
Reason	# of Children	%
Transition to ECSE	1,713	55.0%
Withdrawn from First Steps by Parent/Guardian	306	9.8%
Completion of IFSP prior to reaching maximum age for Part C	300	9.6%
Unable to Contact/Locate	224	7.2%
Moved Out of State	142	4.6%
ECSE Ineligible; Exit to Other Program	121	3.9%
ECSE Eligibility in Process	113	3.6%
ECSE Referral Refused by Parent	93	3.0%
ECSE Ineligible; Exit Without Referral	73	2.3%
Child Deceased	29	0.9%
<b>TOTAL</b>	<b>3,114</b>	<b>100.0%</b>

*For the 2,534 children exiting the First Steps program after reaching at least 2 years, 6 months of age, 67.2% transitioned to ECSE.*



# Costs

## Where does the funding for First Steps come from?

	FY04	FY05	FY06
State Revenue (GR, ECDEC)	\$ 8,303,411	\$ 10,902,838	\$ 13,237,826
Federal Revenue			
— Part B (administration)	\$ 184,685	\$ 184,685	\$ 534,469
— Part C	\$ 7,881,260	\$ 7,746,916*	\$ 8,099,074
Medicaid	\$ 2,218,866	\$ 3,460,122	\$ 4,065,275
Private Insurance	\$ 0	\$ 0	\$ 664,550
Family Cost Participation	\$ 0	\$ 0	\$ 0
Supplemental	\$ 7,363,648	\$ 4,552,794	\$ 0
Other	\$ 173,156	\$ 0	\$ 6,720
<b>TOTAL</b>	<b>\$ 26,125,026</b>	<b>\$ 26,847,355</b>	<b>\$ 26,607,914</b>

## How much was expended for First Steps?

	FY04	FY05	FY06
Early Intervention Services	\$20,448,758	\$18,494,413	\$ 15,508,741
Evaluation/Assessment	Not Available	\$ 807,894	\$ 658,887
Team Meetings	Not Available	\$ 1,025,376	\$ 771,781
Off-System Services	\$ 0	\$ 6,222	\$ 14,149
State Program Administration	\$ 184,685	\$ 184,680	\$ 534,498
Central Finance Office (CFO)	\$ 706,502	\$ 1,037,556	\$ 1,048,328
SPOE Operations	\$ 2,140,914	\$ 3,500,196	\$ 3,913,136
Training/Travel/RICC	\$ 177,125	\$ 148,995	\$ 3,166
Facilitators/Consultants	\$ 351,821	\$ 302,251	\$ 425,111
SICC	\$ 9,014	\$ 10,343	\$ 6,425
Other	\$ 0	\$ 3,466	(\$ 9,937)
<b>TOTAL</b>	<b>\$ 24,018,819</b>	<b>\$ 25,521,381</b>	<b>\$ 22,874,285</b>
<b>Children Served**</b>	<b>7,733</b>	<b>8,282</b>	<b>7,646</b>
<b>Cost Per Child (Total Cost)</b>	<b>\$3,106</b>	<b>\$3,082</b>	<b>\$2,992</b>
<b>Cost Per Child (Direct Services)</b>	<b>\$2,644</b>	<b>\$2,455</b>	<b>\$2,217</b>

Family Cost Participation was implemented in October 2006 as a result of Senate Bill 500 (2005). This legislation requires families to make a nominal monthly payment (unless the family is excluded from payment for specific identified reasons) of between \$5 and \$100 based on the annual income of the family.

Mandated private insurance for Occupational Therapy, Physical Therapy, Speech and Language Therapy and Assistive Technology was also required as a part of SB 500. Implementation of the insurance portion of this legislation began in January, 2006.

\* Federal Part C funds includes a supplemental award of \$14,414 from the prior fiscal year

\*\* This represents the total number of children who had costs incurred in the First Steps system in the given year. Not all of these children received IFSPs—some children incurred only Evaluation/Assessment costs during the eligibility determination process.



# Who Are Our Collaborators?



**MANY PEOPLE, COMMITTEES AND AGENCIES WORK WITH THE FIRST STEPS PROGRAM IN SUPPORTING MISSOURI'S FAMILIES WITH YOUNG CHILDREN, INCLUDING THE FOLLOWING:**

**OFFICE OF THE GOVERNOR**

**MISSOURI GENERAL ASSEMBLY**

**DEPARTMENT OF ELEMENTARY AND SECONDARY EDUCATION**

**DEPARTMENT OF MENTAL HEALTH**

**DEPARTMENT OF SOCIAL SERVICES**

**STATE INTERAGENCY COORDINATING COUNCIL (SICC)**

**REGIONAL INTERAGENCY COORDINATING COUNCILS (RICC)**

**REGIONAL SPOE OFFICES/CONTRACTORS**

**CENTRAL FINANCE OFFICE (CFO)**

**REGIONAL FIRST STEPS CONSULTANTS**

**HUNDREDS OF REFERRAL AGENCIES THROUGHOUT THE STATE OF MISSOURI**

**PARENTS OF CHILDREN ENROLLED IN FIRST STEPS**

**NEARLY 3,000 INDEPENDENT SERVICE PROVIDERS AND PROVIDER AGENCIES  
THROUGHOUT THE STATE**

# Glossary

**Central Finance Office (CFO):** The contracted agency that is responsible for provider payment, child data system design and maintenance, collection of family fees and private insurance billing and other functions as directed by the lead agency.

**First Steps System:** A state-wide system of ten (10) regional areas roughly overlaying the Department of Mental Health (DMH) Regional Centers. The First Steps system is designed to identify, evaluate and provide early intervention services for children birth to three meeting the requirements of Part C of the Individuals with Disabilities Education Act (IDEA).

**Lead Agency:** A designation required by the Individuals with Disabilities Education Act (IDEA) which identifies the state agency responsible for carrying out the requirements of Part C of IDEA. The Department of Elementary and Secondary Education (DESE) has been designated as lead agency.

**Regional First Steps Consultants:** Four regional consultants working under contract provide technical assistance to the SPOE offices, providers, and DMH service coordinators in the areas of child find, provider recruitment, marketing, operations and compliance. They maintain regular communication with the Department of Elementary and Secondary Education in order to coordinate communication between the Department and the SPOE.

**Regional Interagency Coordinating Council (RICC):** A Regional Interagency Coordinating Council is the local coordinating council in each SPOE area. Its purpose is to assist DESE and the SPOE with the evaluation of the effectiveness of the First Steps system within a SPOE region.

**Service Coordinator:** As provided for in Federal and State regulations implementing IDEA, service coordinators:

- Assist parents of eligible children in gaining access to the early intervention services and other services identified in the IFSP
- Coordinate the provision of early intervention services and other services (such as medical services for other than diagnostic and evaluation purposes) that the child needs or is being provided
- Facilitate the timely delivery of available services and
- Continuously seeks the appropriate services and situations necessary to benefit the development of each child being served for the duration of the child's eligibility

**State Interagency Coordinating Council (SICC):** Federal regulations implementing Part C of IDEA require a State Interagency Coordinating Council to advise and assist the state agency in their responsibilities for the First Steps System. This council includes parents, providers, state legislators, and representatives of other state agencies.

**System Point of Entry (SPOE):** The SPOE is the contracted regional administrative office responsible for the operation of all aspects of the state's early intervention system. All children enter the First Steps system through a SPOE.



# County Information

## FY06 Referrals and Active IFSPs by County

COUNTY	FY06 Referrals	Active IFSPs, 12/1/2005
Adair	24	9
Andrew	9	9
Atchison	0	0
Audrain	24	11
Barry	22	15
Barton	9	4
Bates	10	11
Benton	11	3
Bollinger	10	8
Boone	129	100
Buchanan	104	55
Butler	22	17
Caldwell	2	6
Callaway	30	25
Camden	28	9
Cape Girardeau	50	37
Carroll	8	2
Carter	2	2
Cass	73	50
Cedar	13	10
Chariton	6	3
Christian	67	62
Clark	3	4
Clay	223	124
Clinton	17	9
Cole	72	37
Cooper	11	8
Crawford	16	13
Dade	9	3
Dallas	17	7
Daviess	3	5

COUNTY	FY06 Referrals	Active IFSPs, 12/1/2005
Dekalb	3	2
Dent	6	4
Douglas	16	4
Dunklin	13	10
Franklin	81	43
Gasconade	9	4
Gentry	8	3
Greene	218	164
Grundy	4	1
Harrison	5	2
Henry	22	5
Hickory	2	1
Holt	5	6
Howard	4	5
Howell	19	10
Iron	4	6
Jackson	752	484
Jasper	118	58
Jefferson	231	174
Johnson	55	31
Knox	0	0
Laclede	43	27
Lafayette	24	12
Lawrence	28	16
Lewis	6	5
Lincoln	29	20
Linn	8	12
Livingston	8	8
Macon	18	4
Madison	9	8
Maries	5	4



# County Information

## FY06 Referrals and Active IFSPs by County

COUNTY	FY06 Referrals	Active IFSPs, 12/1/2005
Marion	18	13
McDonald	12	10
Mercer	1	0
Miller	12	15
Mississippi	7	5
Moniteau	11	7
Monroe	2	3
Montgomery	12	13
Morgan	9	3
New Madrid	1	2
Newton	32	16
Nodaway	12	6
Oregon	3	3
Osage	13	12
Ozark	2	4
Pemiscot	6	8
Perry	23	14
Pettis	63	30
Phelps	16	27
Pike	14	3
Platte	80	45
Polk	22	19
Pulaski	28	25
Putnam	2	2
Ralls	6	2
Randolph	42	21
Ray	15	8
Reynolds	10	0
Ripley	6	3
Saline	14	13
Schuyler	5	3

COUNTY	FY06 Referrals	Active IFSPs, 12/1/2005
Scotland	4	1
Scott	29	17
Shannon	1	3
Shelby	8	5
St. Charles	452	280
St. Clair	5	6
St. Francois	44	28
St. Louis	817	629
St. Louis City	326	188
Ste. Genevieve	18	9
Stoddard	38	18
Stone	5	7
Sullivan	3	4
Taney	25	16
Texas	7	6
Vernon	17	6
Warren	33	17
Washington	17	9
Wayne	6	3
Webster	43	23
Worth	0	0
Wright	5	5





***“The daily interactions between families and children have a much greater impact on child progress than do early intervention sessions.”***

***— Lee Ann Jung, Ph.D., 2003***

***“Service and intervention are not the same thing. Service is what professionals provide, whereas the majority of the intervention the child receives is from his or her caregiver...”***

***— R.A. McWilliam, Ph.D.***

#### **Contact Information for Missouri First Steps**

Mailing Address:

Missouri Department of Elementary and Secondary Education  
Division of Special Education - First Steps  
P.O. Box 480  
Jefferson City, MO 65102

E-mail Address:

[webreplyspefs@dese.mo.gov](mailto:webreplyspefs@dese.mo.gov)

Phone:

(573) 522-8762

Fax:

(573) 526-5946

#### **To Make a Referral to First Steps**

Toll Free Phone:

(866) 583-2392



The Missouri Department of Elementary and Secondary Education does not discriminate on the basis of race, color, national origin, sex, disability, or age in its programs and activities. Inquiries related to Department programs may be directed to the Jefferson State Office Building, Title IX Coordinator, 5th Floor, 205 Jefferson Street, Jefferson City, Missouri 65102-0480; telephone number 573-751-4581.